

Public preferences for involvement in the governance of health data

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Background:

Public involvement in the governance of epidemiological and public health studies can foster needs-driven research, enhance participants' recruitment, reduce attrition and improve the quality of and ethics in research and surveillance. However, it can also reinforce health inequalities if it fails to ensure public representation across socioeconomic gradients. This study aimed to assess patients' and carers' preferences for involvement in collective health data governance, and its associated factors, to strengthen the evidence base for policy development.

Methods:

Between June 2019 and January 2020, 644 people (157 patients and 487 carers; participation rate=89.3%) followed at two reference centres for rare diseases in a university hospital from Northern Portugal were enrolled in an observational cross-sectional study. Data about willingness to participate in data governance was collected through four intersecting options: periodic or sporadic meetings, by either giving opinions (consultation) or participating in decision-making

(deliberation). Data were analysed using descriptive and inferential statistics.

Results:

From a total of 629 respondents, 39% are willing to get involved through at least one of the four participatory options and 16% do not want to participate. Patients and carers do not differ in their preferences for involvement. Sex and education are associated with willingness to participate, after adjustment for participant type (patient/carer), occupation and trust in national and international institutions (OR:1.60; 95%CI 1.05-2.45 for men vs. women and OR:1.65; 95%CI 1.07-2.56 for >12 vs. ≤12 educational years). Participants' preferred option for participation is consultative sporadic meetings (29.5%).

Conclusions:

Anticipating which social groups are likely to become under-represented in participatory exercises is crucial to inform policy aimed at promoting inclusive involvement in health data governance.

Key messages:

- Men and higher educated participants are more willing to participate.
- Forecasting potential for subgroup under-representation is crucial to develop policy for inclusive participatory data governance.